TASK FORCE ON

ALTERNATIVE HEALTH CARE SERVICES

SUB-COMMITTEE ON PALLIATIVE CARE

INTERIM REPORT

MARCH 25, 1991

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REPORT

ALTERNATIVE HEALTH CARE SERVICES TASK FORCE

SUB-COMMITTEE ON "PALLIATIVE CARE"

The Sub-Committee on "Palliative Care" determined the following broad goals which directed their inquiries and deliberations. They were:

1. To determine palliative care services which currently exist, and to provide palliative care to Manitobans.
2. To delineate gaps which exist in the delivery of palliative care to Manitobans.
3. To define the issues that must be addressed if a comprehensive palliative care program is to be developed in Manitoba.
4. To determine a cost effective approach to the implementation of a comprehensive provincial palliative care program.

EXISTING PALLIATIVE CARE SERVICES IN MANITOBA: AN OVERVIEW.

Attention to the needs of the terminally ill has increased dramatically throughout Canada in recent decades and Manitoba has shared in this phenomena. Efforts to manage pain, to provide comfort and support, and to grant the dying person a sense of autonomy have occurred

provincially on several different fronts. The most extensive response to the needs of the dying person in Manitoba has evolved from hospital based programs. Health care providers have worked through their institutions to develop and coordinate multi-disciplinary approaches to care which have been identified as "palliative care programs". The first in Manitoba to initiate such a program was the Winnipeg Municipal Hospital which, as early as 1950, began a palliative approach supported by physicians from the Manitoba Cancer Treatment Research Foundation and the University of Manitoba. This program has evolved to incorporate designated beds and a link with the Continuing Care Program. In 1974 the St. Boniface Hospital also developed a program with designated beds, coupled with an effective use of the home care services, which enabled the terminally ill person to remain at home for as long as possible. Brandon General Hospital (Assiniboine Centre) started a program in 1981 with beds allocated for palliation and/or treatment of symptoms related to chemotherapy. The Centre does not appear to utilize home care resources to any significant extent. (Data compiled by the office of Continuing Care for a six month period, [April 1/89 to September 30/89], indicated that there were only three referrals from the Brandon Palliative Care Program to the Continuing Care Program during that time period.) The Johnson Memorial Hospital in Gimli initiated a program in 1988. The latter occurred as a demonstration project

through the Health Development Initiatives Fund. One room has been designed to accommodate patient admission for palliation while an adjacent room has been equipped as a sitting lounge. There are other ventures in Palliative Care occurring in rural Manitoba Hospitals, such as the projects underway at the Morden District General Hospital and the Beausejour Hospital. The excellent work begun by these two facilities will be detailed later in this report.
Similarly, other unique hospital based services exist within Winnipeg, such as the Palliative Care Resource Team at Seven Oaks, the Pediatric Oncology Team at Children's Hospital, and the Oncology Department at Victoria Hospital.

Several non-institutional endeavors to meet the needs of the dying also exist within the province of Manitoba. The Continuing Care Program delivers services to terminally ill individuals in the community; it enhances supports in the home enabling people to remain there for periods longer than would otherwise be possible. <u>This is the only program that can provide palliative support province wide, but the extent of its services is limited by its mandate and its structure.</u> Other initiatives centered in Winnipeg include the development of a hospice residence called Jocelyn House, a volunteer recruitment and training organization named The Manitoba Hospice Foundation, and a volunteer support group known as Kali Shiva. The Village Clinic, a community health centre structured to deliver primary care, has dedicated

significant time and resources in the assistance of AIDS victims.

It is obvious from this brief summary that there are positive steps being taken by several players to address the concerns of people who are dying. It is also certain that there are large segments of the population both in Winnipeg and in rural Manitoba who cannot access a formal palliative care program because one does not exist in their area. Furthermore, while there are similarities among programs, there also exist differences in program scope, program direction , and total program cost per client. There is, as well, a divergence in the manner in which both palliative care beds and home care services are utilized from program to program. The issues that need to be addressed then are ones of:

I. policy to ensure the availability of comprehensive palliative care service throughout Manitoba,

II. standard setting in order to ensure quality of care in each program, and

III. utilization of existing resources in a cost effective manner to ensure a comprehensive, yet affordable palliative care service throughout Manitoba.

I: DETERMINING A PROVINCIAL POLICY DIRECTION:

I.1. Program Description and Client Need:

Palliative care is defined in the 1989 Palliative Care Services Guidelines, published by Health and Welfare

Canada, as "a program of active, compassionate care PRIMARILY directed towards improving the quality of life for the dying". It is further described as a service that is "delivered by an interdisciplinary team that provides sensitive and skilled care to meet the physical, psycho-social, and spiritual needs of both the patient and the family". Appendix A, "Functional Classification of A Palliative-Care Program", illustrates the levels of institutional programming that can be achieved according to the various program components that have been defined.

An examination of existing palliative care programs within the province indicates that Manitoba's efforts are in harmony with the directions described above. Furthermore, in studying the various program models and listening to a variety of presenters working in palliative care, the specific client needs to be addressed by a successful program became evident. The majority of terminally ill people who access such programs are cancer patients who share certain common needs.

They need to:

a). obtain effective management of their pain and suffering,

b). know that they can access an appropriate hospital bed located in a reasonable proximity to their own home, when necessary,

c). be assured that their caregivers understand and can cope with the needs of the dying person,

d). access reliable home care services to assist them in remaining in their own homes for as long as possible and, if so desired, to permit them to die at home,

e). have their autonomy, which is protected under the law, respected in regards to the medical interventions they will or will not receive,

f). receive spiritual care and direction,

g). be protected against inadvertent or heroic treatment interventions should they require sudden re-hospitalization,

h). be assured that trained, benevolent volunteers are available as required.

The management of these many defined needs requires multi-disciplinary case management and an integration of community based care with institutional based care. A successful palliative care program must have dedicated physicians as part of the team and there must be, in addition to a community support base, a guarantee of admission, should the need arise, into a designated palliative care bed. For these reasons, and based on the evolution of palliative care services to date, it would seem logical that palliative care programs should be planned to incorporate care in the home or community, yet should be administered from a community or district based hospital. Utilizing community hospitals as a base would keep the institutional part of the service accessible to the client. "Closer to home" is where the client and the family want to be.

RECOMMENDATION 1

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES ADOPT A PROVINCIAL POLICY TO ESTABLISH PALLIATIVE CARE PROGRAMS THROUGHOUT THE PROVINCE AND THAT SUCH POLICY DELINEATE BOTH THE MANDATE AND THE ESSENTIAL COMPONENTS WHICH MUST CONSTITUTE EACH PROGRAM.

I.2. Determining Institutional Bases and Catchment Populations:

While the components of a Palliative Care Program should be consistent whether located in the city of Winnipeg or in a rural area, the manner in which beds are designated and/or the size of facility selected to "house" the program will vary. In the city of Winnipeg, the St. Boniface Palliative Care Unit presents many positive features both in size and to the extent that it has developed the institutional and the community outreach components of its program. The 1985 Report of the Health Services Review Committee contains a report titled "Sub-Committee On The Terminally Ill". This excellent report supports our belief that the resources needed to provide a provincial palliative care service already exist in the health care system. These resources must be mobilized, through policy, into programs that will give all Manitobans who need it, access to palliative care services. Our recommendations differ from

this report on the centers to be used for palliation in the City of Winnipeg in that we believe, based on the presentations we have received, that palliative care programs should be decentralized. Realizing the needs of the clients who will use these beds, it would seem logical to base programs and beds within a community context, so that clients can access palliative care services close to home. While the Palliative Care Guidelines published by Health and Welfare Canada recommend 12 to 15 beds as an optimum size range for palliative care units, units of 15 to 20 beds could be economically more effective and would still be functional. For the Winnipeg area we believe that Community Hospital based programs provide the approach that will keep the bed size of each palliative care program at 20 or less and, at the same time, promote an effective service integration with the Continuing Care Program1.[1] This does not imply that tertiary care facilities should not have palliative care programs, but rather should be developed with a community rather than a referral service in mind. The same should apply to chronic care facilities such as the Winnipeg Municipal Hospital. Furthermore, catchment populations should be determined to define the population to

1. St. Boniface Hospital has a palliative care program with a 25 bed designated unit which supports a client load of 300 patients per year. 120 to 130 clients actively utilize the program at any one time. Cancer patients constitute 90% or more of the user group. The 1988 Annual Statistics Report of the Manitoba Treatment and Research Foundation indicates that there were 2310 cancer related deaths in Manitoba for that year.

be served by each palliative care program in each institution. When determining the catchment population for each program, geographic characteristics, existing service jurisdictions, transportation patterns, population distribution, and the epidemiology of the area should all be considered. Such defined areas would establish eligibility for care and improve accessibility, which would give clients the benefit of being served in their own "neighborhood" and/or the hospital of their choice. A catchment area also defines the responsibility and the accountability of the service provider to the terminally ill clients in their area.

RECOMMENDATION 2

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND THE OFFICE OF CONTINUING CARE DETERMINE POTENTIAL CATCHMENT POPULATIONS TO BE SERVED BY EACH WINNIPEG COMMUNITY HOSPITAL AND THAT PALLIATIVE CARE PROGRAMS BE IMPLEMENTED THROUGH CONSULTATION WITH EACH HOSPITAL.

RECOMMENDATION 3

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND THE OFFICE OF CONTINUING CARE DETERMINE THE EXTENT OF NEED FOR PALLIATIVE CARE PROGRAMS AT THE ST. BONIFACE HOSPITAL, THE HEALTH SCIENCES CENTRE, AND THE WINNIPEG MUNICIPAL HOSPITAL, BASED ON THE

LOCAL COMMUNITY NEEDS THAT THESE FACILITIES SERVE. THIS WILL INCLUDE A DETERMINATION OF THE SIZE AND NUMBER OF UNITS REQUIRED IN EACH LOCATION.

I.3. Ensuring a Community Component Of Care:

The Department of National Health and Welfare, Health Services and Promotion Branch, Sub-Committee on Institutional Program Guidelines, has issued a 1989 publication entitled PALLIATIVE-CARE SERVICES. This document sets out four components of care believed to be essential to a "Core Clinical Service" for palliative care. These components are administration, symptom control, psycho-social support, and spiritual support. The Task Force believes that the incorporation of community care must be added to these four components should palliative care programs be further developed in Manitoba. This is supported by the existing hospital-community models that already exist, such as the program at the St. Boniface Hospital, and by the realization that Manitoba's comprehensive Continuing Care Program can and does provide the resource for the community care component. Community care allows the client to stay at home for lengthened periods with two positive results. First, the client is able to stay where he/she most prefers to be, with family and within his/her own community; second, the need for hospitalization is reduced; with proper management this can be translated into cost savings to the health care system as

a whole. The province of Alberta has a specific program component to its home care program that addresses the needs of those who require palliative care. This component permits some latitude in the amount and type of services that can be delivered to the client in his or her home. It is essential that such service be readily available and able to respond to a client's changing needs in a time-appropriate manner. Based on presentations made from the Office of Continuing Care, it may be that the short term discharge program utilizing the services of the VON would best accommodate the community care needs of the palliative care client who lives in Winnipeg. This, however, would not provide an answer to the delivery of home care services to palliative care clients outside of Winnipeg.

RECOMMENDATION 4

THAT THE OFFICE OF CONTINUING CARE AND THE MANITOBA HEALTH SERVICES COMMISSION DETERMINE THE HOME CARE SERVICES, STAFFING, AND FUNDING RESOURCES REQUIRED TO SUPPORT A PROVINCIAL PALLIATIVE CARE PROGRAM.

I.4. Accessibility To Service:

Palliative care programs must be accessible if clients are to benefit. The only access to existing programs is through a physician's referral; however, even a physician's referral does not guarantee access to the program, nor does

it ensure that an assessment to determine the client's eligibility for the service will occur. Because the role of the family physician is valued and is to be encouraged during the palliative stages of a client's illness, the relationship of the client's personal physician to the palliative care program should be considered when developing each program. This must be done to ensure the role of the family doctor should the client desire it, and to ensure the means of access to the service when the client is in need of it. Continuing Care nurses involved in the delivery of community care for the client must also have avenues through which the services of the palliative care program can be accessed should their client's needs so warrant. The points of entry into palliative care programs must be clearly defined and must be consistent throughout the province. Furthermore, efficient mechanisms for referrals either from the community or from another facility must be established.

RECOMMENDATION 5

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES DEFINE POLICY TO ENSURE THAT ALL MANITOBANS HAVE EQUAL AND UNRESTRICTED ACCESS TO ASSESSMENT TO DETERMINE ELIGIBILITY FOR ADMISSION TO A PALLIATIVE CARE PROGRAM. SUCH POLICY SHOULD BE DETERMINED FOLLOWING CONSULTATION WITH THE INSTITUTIONS AND THE COLLEGE OF PHYSICIANS AND SURGEONS. ONCE ELIGIBILITY HAS

BEEN DETERMINED, ADMISSION MAY BE ARRANGED BY THE CONTINUING CARE STAFF OR THE ATTENDING PHYSICIAN.

I.5. Palliative Care Programs In Rural Areas:

The care needs of the dying do not vary from city to country and palliative services are just as important to rural clients as they are to urban dwellers. The Palliative Care Services Guidelines, Department of National Health and Welfare, suggests two approaches to designating beds for a program. One is by means of establishing units, (a physically self-contained group of hospital beds with its own staff), the other is through a dispersement of designated beds throughout the institution or by aggregating beds in a portion of a larger unit. The value of the later may best be applied to the rural setting where populations, client numbers, and facility size do not justify allocating an entire unit to the service. The development of a palliative care team can occur in rural facilities and bed designations can be in the form of "swing beds" or in the allocation of a small number of rooms.

The rural hospital in Beausejour began a palliative care program in the fall of 1989. This was in response to the high incidence of cancer in the area and the belief among health professionals that clients in the terminal stages of illness were entitled to services which would maximize their quality of life and allow them to remain at home for as long as possible. The administrative task was

to consolidate and direct the efforts of existing resources to facilitate this. A team was formed consisting of the hospital administrator, the director of nursing, a staff nurse, a physician who had special interest and training in palliative care, the Continuing Care co-ordinators for the area, a community pastor, and a volunteer resource coordinator. This group has established a structure that encompasses the components required for a palliative care program, as set forth in section 6 of the Palliative Care Services Guidelines published by the Department of National Health and Welfare. Factors fundamental to their initial success would appear to be the strong commitment given by the hospital administration, the physician, and the Continuing Care staff within the region, as well as a local nurse who volunteered to serve as a program co-ordinator. These observations in no way disregard the significant contributions of others to the program, but are intended to point out the essential commitment that must exist between administration, physicians and Continuing Care if a meaningful program is to have any chance of developing. Beausejour has successfully relied upon the Continuing Care Co-ordinator to initiate referrals to the program based on his/her assessment of need. This individual meets monthly with the rest of the team to participate in the identification of clients, and the review and recommendations for appropriate interventions. He/she also attends weekly discharge rounds at the hospital to discuss

arrangements for returning clients back to their homes. This latter is most significant in managing bed utilization for the hospital. The hospital, served by five physicians, has designated eight of its thirty beds as swing beds to be used for long term and palliative care. The demands for these beds is significant as utilization studies reflect a 90% occupancy rate. Discharge management is vital to ensure admission, when needed, to any palliative care client.

The Morden District Hospital has also initiated a palliative care program. It focuses on a volunteer program to provide client support and has designated one bed in the facility as a palliative care bed. Like Beausejour, it possesses strong commitment from administration, and physicians, and has established effective working links with Continuing Care. The Morden program has negotiated social worker support from Eden Mental Health Centre, rather than utilizing services from the Central Region.

It is evident that the essential resources needed to facilitate the development of palliative care programs and services do exist in the rural areas. Rural models are now in formation through the efforts of the rural facilities described above. The Task Force believes that provincial policy should exist to promote this development throughout the regions in rural Manitoba. The province needs to catalyze the interests and efforts of health professionals throughout the province so that palliative care services

will be mobilized to the benefit of all Manitobans who may need the service.

RECOMMENDATION 6

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES ESTABLISH POLICY THAT WILL PROMOTE AND DIRECT THE DEVELOPMENT OF PALLIATIVE CARE SERVICES IN EACH GEOGRAPHIC RURAL HEALTH REGION, UTILIZING THE RESOURCES AVAILABLE THROUGH THE REGIONAL OPERATIONS OF COMMUNITY HEALTH SERVICES.

RECOMMENDATION 7

THAT POLICY ADDRESSING THE INTEGRATED USE OF INSTITUTIONAL AND COMMUNITY RESOURCES FOR PALLIATIVE CARE PROGRAMS, AND THE METHODS OF CLIENT REFERRAL AND ACCESS TO SUCH PROGRAMS, BE SENT TO THE COMMUNITY INSTITUTIONAL INTERFACE COMMITTEE OF THE DEPARTMENT OF HEALTH FOR ENDORSEMENT AND SUPPORT.

I.6. Rural Program Development:

In his address on "The Continuum of Care" delivered at the 1990 Manitoba Health Conference in Winnipeg, Mr. Paul A. Pollen, Executive Director of the B.C. Continuing Care Division, observed that "informal cooperation and working together is essential to implementing change.---Rearranging

boxes on an organizational chart won't make it (change) happen.---Governments should be supportive and serve as a catalyst (for change).---Communities need to take the leadership role". Effective use of allocated resources depends upon the ability of the governing boards, administrations, and regional directors to develop strategic plans for delivery of health care programs within regions and communities. Provincial policies and various legislative acts provide the parameters in which resources can be used. However, the benefits to be derived from these resources depend upon the co-operation and vision of those who implement and deliver the actual health care services to Manitobans. It would be "neat and tidy" if this Task Force could recommend which rural facilities should develop palliative care services in each geographic region, but such an action could not guarantee results. Effective program development will require initiative from the institution and the region itself. Unless there exists effective medical and nursing leadership, commitment from community health services and the administrative will to designate institutional beds, an effective palliative care program is unlikely to emerge. In addition to these essential ingredients there should exist within the community an ability to generate a trained, volunteer support group, and to develop a committed pastoral care service.

There are six rural facilities that provide a chemotherapy treatment service which has been established

through the Chemotherapy Outreach Program of the Manitoba Cancer Treatment and Research Foundation. Placement of this service is dependent upon determining a catchment area from which 25 or more new cancer patients requiring treatment appear each year. Most palliative care clients are cancer victims, so one might project that palliative programs might logically ensue from these centers. The philosophies of the two efforts, however, may represent a dichotomy. Chemotherapy programs are intended to arrest and to cure the disease, while palliative care programs are intended to provide compassionate care directed towards improving the quality of life for the dying person. Facilities providing chemotherapy services may or may not accommodate both philosophies in their client approach, but where they do, it would seem natural for them to progress towards the development of a formal palliative care program. There could be several facilities who do not qualify for a chemotherapy program that could also work towards development of palliation services. The root requirements must be dedication to the palliative philosophy of care for the terminally ill and the presence of clients who could benefit from the service. The latter again calls for identification of need within a defined catchment area.

RECOMMENDATION 8

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES STRIVE TO IDENTIFY

SUITABLE RURAL CATCHMENT AREAS THAT WOULD JUSTIFY THE NEED FOR A PALLIATIVE CARE PROGRAM BASED ON IDENTIFIED CLIENT NEED.

RECOMMENDATION 9

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES IDENTIFY APPROPRIATE FACILITIES WITHIN EACH CATCHMENT AREA WHICH COULD SERVE AS A SUITABLE BASE FOR A PALLIATIVE CARE PROGRAM.

RECOMMENDATION 10

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES IDENTIFY PROGRAM SUPPORTS NECESSARY TO FACILITATE THE DEVELOPMENT OF SUCH PROGRAMS.

RECOMMENDATION 11

THAT THE COMMUNITY INSTITUTIONAL INTERFACE COMMITTEE USE ITS "PARTNERSHIP PROCESS" TO ENCOURAGE THE INSTITUTIONAL AND COMMUNITY SECTORS TO RESPOND TO THE NEED FOR PALLIATIVE CARE PROGRAMS IN EACH REGION, AND TO MOBILIZE EXISTING RESOURCES INTO EFFECTIVE PROGRAMS.

RECOMMENDATION 12

THAT THE MANITOBA HEALTH ORGANIZATION (MHO) BE ENCOURAGED TO HOLD DISCUSSIONS AMONG THEIR RURAL

MEMBERS THAT WOULD FACILITATE THE DEVELOPMENT OF THIS MUCH NEEDED RURAL SERVICE.

II. ENSURING STANDARDS FOR A PALLIATIVE CARE SERVICE

II.1. Establishing Standards of Practice:

It is important that provincial guidelines and standards of practice be developed for palliative care programs in Manitoba to ensure the quality of care to be delivered by this service. The work of the "Subcommittee on Institutional Program Guidelines" is a national effort which has been referred to before in this document. It should provide a basis from which Manitoba can set guidelines and develop minimum standards for all palliative care programs in the province. It is also of great importance that the College of Physicians of Manitoba display leadership in developing the standards of medical practice that will direct medical efforts in the management of terminally ill persons. This was called for in the Report of the Health Services Review Committee in its "Sub-Committee Report on the Terminally Ill", (page 430, first recommendation). The Task Force supports this recommendation and reiterates it. Patient autonomy must be respected in the decision to treat, and the impact of invasive treatments must be evaluated against the quality of life that the client will have. The World Health Organization's Collaborative Centre on Quality of Life, located at St. Boniface Hospital under the direction of Dr. Harvey Schipper, is working specifically in

this area and may well be able to offer assistance in the development of standards. Furthermore, standards of nursing practice in the implementation of palliative care will also be of value in defining the role of the professional nurse as a major care giver.

RECOMMENDATION 13

THAT THE MANITOBA HEALTH SERVICES COMMISSION IN CONSULTATION WITH THE OFFICE OF CONTINUING CARE, DEVELOP GUIDELINES AND STANDARDS OF SERVICE FOR PALLIATIVE CARE PROGRAMS IN MANITOBA.

RECOMMENDATION 14

THAT THE COLLEGE OF PHYSICIANS OF MANITOBA, IN CONSULTATION WITH COMMUNITY REPRESENTATIVES, DEVELOP STANDARDS OF MEDICAL CARE FOR THE TERMINALLY ILL THAT WILL ENSURE QUALITY CARE AND THAT WILL CONSIDER THE PATIENT'S RIGHT TO QUALITY OF LIFE.

RECOMMENDATION 15

THAT THE MANITOBA ASSOCIATION OF REGISTERED NURSES, IN CONSULTATION WITH COMMUNITY REPRESENTATIVES, DEVELOP STANDARDS OF NURSING CARE FOR THE TERMINALLY ILL PATIENT THAT WILL FACILITATE AND DIRECT THE NURSING CARE OF THESE PATIENTS.

II.2. Education and Training:

Initial education of professional staff is critical to the development of a successful palliative care program. Staff will also need access to continuing education. There is value in establishing a central location where information can be gathered and shared, and where initial training can be offered.

RECOMMENDATION 16

THAT THE MANITOBA HEALTH SERVICE COMMISSION AND COMMUNITY HEALTH SERVICES ESTABLISH, THROUGH CONSULTATION WITH PROFESSIONALS WORKING IN PALLIATION, THE TRAINING REQUIRED FOR PROFESSIONAL MEMBERS OF THE MULTI-DISCIPLINARY TEAM PRIOR TO THE ESTABLISHMENT OF A PALLIATIVE CARE PROGRAM.

RECOMMENDATION 17

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES DETERMINE THE MECHANISMS AND RESOURCES NECESSARY TO ENABLE SUCH TRAINING TO OCCUR.

II.3. The Role of Other Provincial Organizations:

The Canadian Cancer Society, Manitoba Division, can and does play an educative role regarding the needs of palliative patients. The Manitoba Hospice Foundation is an organization centered in Winnipeg dedicated to addressing the needs of the terminally ill through "care, education and

co-ordination of related programs in Manitoba". The Foundation believes it has the structure in place to serve as a provincial association and this past year hosted a provincial conference on hospice care. The Foundation has developed a thorough education program for volunteer training and has assisted various communities and facilities with training. Their role as a training resource for members of newly formed palliative care programs should be explored. They are currently funded through donations and various grants. Should the province rely on the Manitoba Hospice Foundation to assume an expanded role in the provision of inservice and training for staff working in palliative care programs, their funding would need to be augmented and the expectations for additional service would have to be established.

RECOMMENDATION 18

THAT PROVINCIAL ORGANIZATIONS SUCH AS THE MANITOBA DIVISION OF THE CANADIAN CANCER SOCIETY AND THE MANITOBA HOSPICE FOUNDATION BE ENCOURAGED TO EXAMINE THEIR ABILITY TO CONTRIBUTE TO PALLIATIVE CARE WITHIN THE PROVINCE IN THE FOLLOWING AREAS:

a). EDUCATION OF THE PUBLIC,

b). ESTABLISHMENT OF STANDARDS,

c). AS AN ADVOCATE FOR THE PATIENT'S RIGHT TO PALLIATIVE CARE.

III. Economic Or Cost Considerations:

The Task Force was most interested to learn that palliative care programs had been established at both Beausejour and Morden, utilizing existing resources. There has been prior mention in this report regarding the existence of necessary resources within the system to address the needs of the terminally ill client. In fact, if successful palliative care programs were established both in the rural and urban areas, as suggested in this report, we believe there are cost savings to be obtained in three ways:

1. Effective programming should prevent costly acute care interventions from occurring when caring for people in the end stage of a terminal illness. (Diagnosis, prognosis, and the determination of a treatment regime in full consultation with the client and family is critical here).

2. Effective programming should increase the ability of clients to remain in their own homes, which should shorten their length of stays when in hospital. Per diem costs within hospitals are generally far higher than the per diem cost of maintaining a client in their own home. Savings can be effected only if the use of the hospital bed is properly managed.

3. Effective programming in Winnipeg should result in hospitals designating beds for a palliative care unit from the institutional beds presently in operation. This will decrease the number of acute care beds in the facility, which should in turn control the high costs associated with

admission to such beds. Designated palliative care units will regulate the use of beds assigned to the unit specifically for a palliative purpose, and can be funded accordingly. Designated palliative care units should be provided with "flex" staffing to accommodate the actual care needs on the unit during any given shift. This permits quality care to be delivered in a cost efficient manner.

RECOMMENDATION 19

THAT COST SAVINGS REALIZED THROUGH THE DESIGNATION OF BEDS IN PALLIATIVE CARE UNITS BE UTILIZED TO OFF-SET OTHER COSTS REALIZED BY THE PROGRAM.

Effective utilization of home care should effect savings in the care of the terminally ill, but this is dependent upon the efficient management of the institutional beds designated to the program. While total costs incurred to deliver service should decrease, the actual cost of home care services may well increase, as that service is more fully utilized. This may require adjustments in the budget for the Winnipeg Short Term Home Care Program and for some Home Care Programs in rural regions.

RECOMMENDATION 20

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES NEGOTIATE THE TRANSFER OF FUNDING FROM THE INSTITUTIONAL SECTOR TO THE

COMMUNITY FOR EACH NEW PALLIATIVE CARE PROGRAM IN MANITOBA.

Therapeutic nutrition, pain control, and other symptom management is a critical requirement for any effective palliative care approach. Nutritional supplements, as well as narcotic and antiemetic drugs found to be effective in obtaining symptomatic relief, are very costly. Since developing palliative care programs, both Beausejour and Morden hospitals have experienced dramatic increases in costs related to the use of drugs for pain and symptom control. While adequate pain and symptom control results in significant increases in drug costs, these are legitimate and necessary if palliation is to be achieved. The 1990 Final Report of The Needs of Persons Living With Cancer in Manitoba published by the Canadian Cancer Society, October 1990, addresses the reality of "unmanaged pain control" which many cancer patients face. They include: "Clearly more effective pain management is an area to which attention should be directed."

RECOMMENDATION 21

THAT MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES FUNDING TO PALLIATIVE CARE UNITS MAKE PROVISION FOR JUSTIFIABLE COSTS, INCURRED BOTH IN THE HOSPITAL AND IN THE HOME, FOR THERAPEUTIC NUTRITION, AND THE DRUGS REQUIRED FOR

THE MANAGEMENT OF PAIN AND OTHER SYMPTOMS EXPERIENCED BY MANY TERMINALLY ILL CLIENTS.

RECOMMENDATION 22

THAT COSTS FOR THERAPEUTIC NUTRITION AND THE MANAGEMENT OF PAIN AND OTHER SYMPTOMS BE FUNDED IN FULL FOR THOSE CLIENTS ADMITTED TO A PALLIATIVE CARE PROGRAM.

Volunteers contribute to care through the donation of time, energy, and compassion on behalf of others. Palliative care programmers realize that volunteer services play an important role in meeting the needs of the client and the family. Frequently the family members are in need of support even when the client may not show a direct interest in having a volunteer visit on a regular basis. Bereavement support to the spouse and family is also believed to be of significant benefit following the death of a loved one. Many clients are elderly and death leaves an elderly spouse alone at a time when he/she is most vulnerable. Continued volunteer support can be invaluable during those first lonely months, can help sustain the spouse and may prevent frequent medical visits or even hospitalization. The time donated through volunteer work for palliative care constitutes hours of unpaid service in the area of health care. To be effective, volunteer support programs must have a qualified volunteer coordinator to recruit, train, support, and oversee the activities of the

volunteers. This may be a salaried person, or a volunteer, in either a part time or a full time position. Some facilities have obtained salary dollars for a volunteer coordinator through grants and community donations. This is laudable and should be encouraged. Because the service is of such benefit, some permanent funds should be assigned to promote its development.

RECOMMENDATION 23

THAT THE MANITOBA HEALTH SERVICES COMMISSION AND COMMUNITY HEALTH SERVICES DETERMINE PROGRAM RESOURCES REQUIRED TO FACILITATE THE RECRUITMENT, PREPARATION, AND COORDINATION OF VOLUNTEERS FOR PALLIATIVE CARE PROGRAMS.

HOSPICE RESIDENCES AS AN ALTERNATIVE SERVICE:

The hospice philosophy incorporates a multi-disciplinary approach to providing care within a home-like residence, where compassionate care and support assists the client both in meaningful living and in preparation for death. Hospice residences are viewed as an optional living choice for terminally ill clients who are unable to remain in their own home, but who desire to remain in a "home-like" atmosphere. Jocelyn House, situated along the Seine River in St. Vital, is the only Hospice Residence in Manitoba. It contains five individual client rooms and runs at a 75%

occupancy rate. Clients pay a monthly rate of $750 for an average length of stay of two to three months.

Through the Continuing Care Program, VON nurses provide nursing services to those residents of Jocelyn House who require the services. While in the facility VON nurses provide consultation to other staff providing care to residents. Jocelyn House receives an annual grant from the Manitoba Government and relies on donations for the balance of its operation. The administration and board prefer to remain licensed under the Residential Care Act and fear that any direct line funding from government would inflict unrealistic standards and curtail their freedom to program. Jocelyn House has habitual openings and a non-existent waiting list. Their Administrator checks with Winnipeg Hospitals weekly to let them know of vacancies within the Hospice. Jocelyn House does receive some referrals from St. Boniface Hospital and from the Winnipeg Municipal Hospital. While the board indicates their willingness to admit clients suffering from AIDS, this has yet to happen. Jocelyn House is offering an alternative home for select clients who lack a support group, and who are in the terminal stages of illness. The absence of a waiting list and the 75% occupancy suggests that Winnipeg is not in need of additional hospice residences. The Task Force believes that the majority of terminally ill people wish to remain in their own homes unless hospitalization is imperative, and

believes that provincial policy should be directed towards that end.

AIDS VICTIMS IN MANITOBA:

Two hundred and sixty people living in Manitoba are currently known to be HIV positive. Presenters from the Village Clinic shared their concern that many more undiagnosed or unknown cases may in fact exist. No statistics, including those from Village Clinic, are available to verify this. There are presently one to two AIDS victims in Manitoba requiring palliative care. Based on the data available, it would appear that a palliative care program for Manitoba, as suggested in this document, would be able to accommodate the needs of AIDS patients who progress to the palliative stage. This however, would require additional staff and volunteer training. The Task Force feels that special efforts in the form of palliative accommodations or palliative programs unique to AIDS sufferers would be unwise at this time. Health care dollars, to be spent wisely, should address a palliative care program that encompasses the needs of all Manitobans who are terminally ill and face death. This, we believe, will best utilize existing funds and will prudently direct any new funds that may become available.

RECOMMENDATION 24

THAT ADDITIONAL EDUCATION AND TRAINING IN THE MANAGEMENT OF AIDS PATIENTS BE SUPPORTED FOR THOSE PALLIATIVE CARE PROGRAMS WHICH HAVE AIDS PATIENTS AS PART OF THEIR CATCHMENT POPULATION.

CONCLUSION

It is the belief of this Task Force, based on numerous presentations, a studied consideration of the recommendations of the Health Services Review Committee, a review of the 1989 report on Palliative Care Services prepared by the Office of Continuing Care and other sources referenced in this report, that the resources required to deliver an effective palliative care program in Manitoba are already present. Policy development, integrated program planning and management, and the reallocation of some funds are needed to mobilize these resources into an effective palliative care program throughout Manitoba. This will require the will, vision, and commitment of the many professional disciplines that provide health care service in each community and health region throughout Manitoba. We urge the health care leaders of this province to determine the policy and the strategy that will allow this to happen. We further urge administrations, physicians, and other health care professionals to recognize and accept both the challenge and the opportunity that such policy will bring.

Guidelines for Establishing Standards

6. FUNCTIONAL CLASSIFICATION OF A PALLIATIVE-CARE PROGRAM

The previously described components may be used to classify the functional level of a palliative-care program into one of the following categories:

Program Components	Preliminary Program (Note 1)	Level I-Core Clinical Program (Note 2)	Level II - Complete Program (Note 3)
1. Administration*	*Lack of one or more of the first four components	Required	Required
2. Symptom Control*		Required	Required
3. Psycho-social Support*		Required	Required
4. Spiritual Support*		Required	Required
5. Volunteers			Required
6. Bereavement Support			Required
7. Program Evaluation			Required
8. Training and Education			Required

Note 1: A Preliminary Program lacks one or more of the first four components.

Note 2: A Level I Core Clinical Program must at least have the first four components fully developed and functioning.

Note 3: A Level II Complete Program must have all components fully developed and functioning.

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Presentations were received from the following sources:

1. Beausejour Hospital, Palliative Care Program,---group presentation.

2. Jocelyn House---Mr. Al Holt, Executive Director.

3. Johnson Memorial Hospital, Palliative Care Program,---group presentation.

4. Manitoba Health Services Commission---Mr. Frank DeCock, Executive Director.

5. Manitoba Hospice Foundation, Margaret Clark, Director.

6. Morden District Hospital, Palliative Care Program,---group presentation.

7. Office of Continuing Care,---Ms. Margaret Barbour, Acting Director.

8. St. Boniface Hospital, Palliative Care Unit,---Dr. Paul Henteleff.

9. Village Clinic---group presentation.

10. Winnipeg Municipal Hospital, Palliative/Oncology Unit, Mr. Denis St. Laurent, Nursing Unit Manager.

References:

1. Overview of Palliative Care in the Province of Manitoba. Feb. 20, 1990. Report prepared by the Office of Continuing Care for the Community Institutional Interface Committee, Manitoba Health, Winnipeg.

2. Palliative Care Services Guidelines, 1989. Health Services Directorate, Health Services and Promotion Branch, Dept. of National Health and Welfare, Ottawa.

3. Pellon, P. November 1990. Continuum of Care Address to the Manitoba Health Conference, Winnipeg, Manitoba.

4. Report of the Health Services Review Committee, 1985. Sub-Committee on the Terminally Ill. Government of Manitoba, Winnipeg.

5. Richardson, B. G., 1990. Overview of Provincial Home Care Programs in Canada. Forum.

6. Vachon, Lancee, Conway, and Adair, 1990. Final Report on the Needs of Persons Living With Cancer in Manitoba. Commissioned by the Manitoba Division and the National Board of the Canadian Cancer Society.